







September 19, 2012

The Health Care Reform Implementation Council

Re: Comments on Establishing Essential Health Benefits Package (EHB): What Policymakers Can Do to Ensure Access, Quality and Affordability for Cancer Patients in Illinois

Dear HCRIC:

Thank you for the opportunity to submit comments on defining the essential health benefits package for the state of Illinois. The health care needs of cancer patients are the needs of those both with serious, life-threatening illnesses and chronic health care issues. Treating cancer involves accessing a complex and extensive set of health care services including chemotherapy and prescription drugs, among others. These long-term treatment services can place great financial burden upon patients due to the cost sharing burdens associated with care, even if they are insured.

Both insured and uninsured Illinois cancer patients and survivors are among those who will benefit greatly from the implementation of an Affordable Health Benefit Health Exchange, as part of implementation of the federal Affordable Care Act (ACA). The U.S. Department of Health and Human Services (HHS) will soon release federal rules regarding establishment of state EHBs, but they are not expected to be overly prescriptive, leaving most of the details in the hands of state decision makers.

Unless policymakers in Illinois provide affordable access to comprehensive care, the promise of the ACA will not become reality for cancer patients or survivors. If the state's essential health benefit (EHB) package leans too heavily toward maximizing flexibility at the expense of ensuring access to comprehensive and quality cancer care, cancer patients may find themselves having insurance that is inadequate to meet their health care needs, while being saddled with crippling financial responsibility for their care.

Illinois has demonstrated its commitment to cancer patients by enacting legislation that improves the care of cancer patients. We strongly urge the state to include its existing set of cancer mandates including but not limited to equal coverage for oral cancer treatments (HB1825), clinical trials (HB 1191), and other cancer patient pharmacy needs. In addition, please select a benchmark plan that also meets the Illinois statutory requirement to include standard medical necessity language in its contracts.

We also encourage Illinois to continue to promote transparency and oversight as the selected benchmark is used to determine covered items and services in individual and small group plans offered on and off the Exchange. This remains necessary to prevent actuarially equivalent substitutions that could deter individuals with complex health care needs from enrolling. It is

also important in order to ensure transparency regarding the use of inside limits and to monitor the application of burdensome prior authorization requirements.

The State Patients Equal Access Coalition (SPEAC) is a patient-focused coalition of organizations representing patients, health care professionals, and cancer care centers, working collaboratively to ensure that cancer patients have appropriate access to a broad range of approved and medically-accepted anticancer regimens including, but not limited to oral and intravenous drugs, injections, surgery, radiation, transfusions, transplantation, and palliative care. SPEAC believes that every cancer patient should have access to the anticancer regimens recommended by their physician and should not suffer from cost discrimination based on the type of therapy provided or the mechanism of delivery.

We, the undersigned, offer the following road map to policymakers when setting the standards for the state's Health Exchange and EHB package. If you have any questions, please contact Meghan Buzby, International Myeloma Foundation, at 410-252-3457 or mbuzby@myeloma.org.

Sincerely,

Association of Community Cancer Centers International Myeloma Foundation National Brain Tumor Society Susan G. Komen for the Cure Advocacy Alliance The Leukemia & Lymphoma Society The Lymphoma Research Foundation









A Road Map to Comprehensive Cancer Care for Illinois

TREATMENT

- All elements of multi-disciplinary treatment, as recommended by the patient's care team and supported by available evidence, including:
 - o Drugs and biologicals, whether physician-administered or self-administered.
 - Drugs and biologicals for off-label uses, according to the evidence-based standards utilized in the Medicare program.
- Pharmacy Benefit That Includes:
 - Prescription drug coverage with full coverage of the six protected classes, offering more than one drug per class and as defined in the Medicare Part D program.
 - Patient appeals process and care coordination and transition planning for patients taking a specific drug if it is not on their new plan's formulary.
 - Formulary standards that require inclusion of multiple drugs in a range of therapeutic categories and comprehensive coverage for therapies needed by the most vulnerable patients.
 - Independent Pharmacy and Therapeutic (P&T) Committees that review the drugs included on those formularies, as well as the utilization management requirements for such drugs, and consider newly approved treatments and indications for inclusion in formularies within certain timeframes such as those required under Part D.
 - A mechanism for incorporating new therapeutic categories or classes in order to protect patients' access to innovative therapies as they become available.
- Equal treatment of out-of-pocket expense to patients receiving intravenous, injectable, and/or orally-administered oncolytic treatments. Compliance cannot be achieved by imposing an increase in patient cost sharing, including any copayment, deductible or coinsurance, for oncolytic treatments whether intravenously administered or injected or orally administered.
- Prohibit the use of excessive cost-sharing required by prescription drug benefit designs
 that utilize specialty tiers; out-of-pocket costs for prescription drug coverage should be
 transparent and included in the out-of-pocket limits pursuant to the ACA requirements.
- Monitor the use of tiered networks that may discriminate against patients with specialty drug needs.
- Use Exchange information technology requirements and operating authorities to assure rapid access to appropriate drugs by all plans offered under the Exchange.